APPENDIX E

Modified 3/2021

Contents

[1 ESSENTIAL QUESTIONNAIRE - 4 -](#_Toc65877348)

[1.1 REGISTRATION - 4 -](#_Toc65877349)

[1.2 DEMOGRAPHY - 5 -](#_Toc65877350)

[1.3 LIFESTYLE FACTORS - 7 -](#_Toc65877351)

[1.4 ENVIRONMENTAL FACTORS - 9 -](#_Toc65877352)

[1.5 ALS-ASSOCIATED AND CLINICAL FACTORS - 12 -](#_Toc65877353)

[2 FOLLOW-UP QUESTIONS 14](#_Toc65877354)

[2.1 REGISTRATION 14](#_Toc65877355)

[2.2 DEMOGRAPHY 14](#_Toc65877357)

[2.3 LIFESTYLE INFORMATION 15](#_Toc65877358)

[2.4 EVIRONMENTAL FACTORS - 26 -](#_Toc65877359)

[2.5 ALS-ASSOCIATED AND CLINICAL FACTORS - 71 -](#_Toc65877429)

APPENDIX E

Surveys

ONE TIME SURVEYS

Questionnaire to be divided into Essential Questionnaire (Part I) and Follow-up Questions (Part II) by topic

General Instructions (on a separate screen before starting the survey)

**How to fill in answers:**

* Please read each survey question carefully and answer to the best of your knowledge.
* Answers to questions come in several formats:
* Radio button and drop-down selections allow only one input per question.
* Check box selections allow multiple answers per question.
* Text boxes allow you to type in an answer. Text box entries are identified as an empty box or selection labeled “Other (specify)”.
* Some questions within each survey will appear “grayed-out” because of your answer to an earlier question. These questions do not apply to you and you can continue onto the next survey question or page.

**How the system works:**

* When Essential Questionnaire (Part I) is completed and submitted, it’ll be followed by set of additional questions (Part II) asking for more detailed information regarding your demography, lifestyle, environmental, and ALS-associated factors. Follow-up questions are based on the responses from Part I.
* Each time you go to the next page of a survey your answers to the previous page are saved.
* You are given the option to save and quit a survey at anytime. Once you decide to save and quit the survey your responses are saved and you can finish the survey later.
* At the end of each survey, you are given the option to review and change your answers. You can also print a copy of your answers. Once you submit your answers, you will not be able to change or print them later.
* There is no time limit to take surveys. However, if you stay logged in and do not work on the survey an alert will display. You will be informed that your session will time out if no further activity takes place.

***The purpose of this questionnaire is to obtain some general information about your demography, as well as information on lifestyle, environmental, and ALS-associated factors.***

# ESSENTIAL QUESTIONNAIRE

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **EQ** | **Item** | **Responses** | **Origin** | **Follow-up** |
| 1 | Username (or REG\_ID) |  | Registration |  |
| 2 | Date of diagnosis | MM/YYYY | Registration |  |
| 3 | Date of Registration | MM/DD/YYYY | Registration |  |
| 4 | Title | |  | | --- | | 1🖵 Mr  2🖵 Ms  3🖵 Miss  4🖵 Mrs  5🖵 Dr | |  |  |
| 5 | First name |  | Registration |  |
| 6 | Middle initial |  | Registration |  |
| 7 | Last name |  | Registration |  |
| 8 | Suffix | |  | | --- | | 1🖵 Jr  2🖵 Sr  3🖵 I  4🖵 II  5🖵 III  6🖵 IV | | Registration |  |
| 9 | Last 5 digits of SSN |  | Registration |  |
| 10 | Current country |  | Registration |  |
| 11 | Current state/province (in US/Canada) |  | Registration |  |
| 12 | Current province (outside US/Canada |  | Registration |  |
| 13 | Current City |  | Registration |  |
| 14 | Email |  | Registration |  |
| 15 | Are you interested in receiving any of the following? (check all that apply) | 0🖵 No  1🖵 Registry email  2🖵 Research notification information | Registration |  |
| 16 | Have you participated in any ALS research studies? | 1🖵 Yes  2🖵 No  9🖵 Don’t know | Survey 17 |  |
| 17 | Are you interest in participating in any ALS research studies | 1🖵 Yes  2🖵 No  9🖵 Don’t know | Survey 17 |  |

## REGISTRATION

## DEMOGRAPHY

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **EQ** | **Item** | **Responses** | **Origin** | **Follow-up** |
| 1 | Gender | 1🖵 Male  2🖵 Female 🡪 | Survey 1 | Survey 12 |
| 2a | Birth month | 1🖵 January  2🖵 February  3🖵 March  4🖵 April  5🖵 May  6🖵 June  7🖵 July  8🖵 August  9🖵 September  10🖵 October  11🖵 November  12🖵 December | Registration |  |
| 2b | Birth year |  | Registration |  |
| 3 | Current marital status | 1🖵 Never married  2🖵 Married  3🖵 Separated  4🖵 Divorced  5🖵 Widowed  6🖵 Living with partner | Survey 1 |  |
| 4 | Highest level of education attained | 1🖵 Did not complete High School; Less than 12th grade  2🖵 High school diploma or GED  3🖵 Technical or trade school diploma  4🖵 Some college credit or AA degree  5🖵 College degree  6🖵 Graduate School degree  7🖵 Other | Survey 1 |  |
| 5 | Do you consider yourself Spanish, Hispanic, or Latino/Latina? | 1🖵 No  2🖵 Puerto Rican  3🖵 Mexican, Mexican-American, Chicano  4🖵 Cuban  5🖵 Other Spanish, Hispanic (specify) | Survey 1 | Question 7 |
| 6 | What do you consider to be your race or ethnic group? (Check all that apply) | 1🖵 White  2🖵 African American  3🖵 Native American/Alaskan Native  4🖵 Asian Indian  5🖵 Chinese  6🖵 Filipino  7🖵 Japanese  8🖵 Korean  9🖵 Vietnamese  10🖵 Other Asian (specify)  11🖵 Native Hawaiian  12🖵 Guamanian or Chamorro  13🖵 Samoan  14🖵 Another Pacific Islander (specify)  15🖵 Don’t know | Survey 1 |  |
| 7 | Country of birth |  | Survey 1 |  |

## LIFESTYLE FACTORS

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **EQ** | **Item** | **Responses** | **Origin** | **Follow-up** |
| 1a | Current height (ft) |  | Survey 1 |  |
| 1b | Current height (in) |  | Survey 1 |  |
| 2 | Current weight (pounds) |  | Survey 1 |  |
| 3 | Have you ever smoked one or more cigarettes per day for 6 months or longer? | 1🖵 Yes 🡪  2🖵 No  9🖵 Don’t know | Survey 4 | Question 2-6 |
| 4 | Did you ever drink alcoholic beverages such as wine, beer and spirits at least once a month for 6 months or more | 1🖵 Yes 🡪  2🖵 No  9🖵 Don’t know | Survey 4 | Question 8-10 |
| 5 | Have you ever engaged in vigorous leisure-time physical activity for at least 10 minutes that caused heavy sweating or large increases in breathing or heart rate | 1🖵 Yes 🡪  2🖵 No  9🖵 Don’t know | Survey 5 | Question 2 |
| 6 | Did you ever drink caffeinated beverage? (Check all that apply) | 0🖵 No  1🖵 Espresso or expresso drinks (Latte, Americano)  2🖵 Regular coffee  3🖵 Hot or cold tea (Black, green)  4🖵 Highly caffeinated (Jolt®, Surge®, Mountain Dew MDX®, Red Bull® or other energy drinks)  5🖵 Regular soda (Barq’s Root Beer ® or regular Mountain Dew®)  6🖵 Don’t know | Survey 13 | Box Row 1  Box Row 2  Box Row 3  Box Row 4  Box Row 5 |
| 7 | Have you participated in organized or professional sports? (Check all that apply) | 0🖵 No  1🖵 Football  2🖵 Hockey  3🖵 Boxing  4🖵 Soccer  5🖵 Other sports  6🖵 Don’t know | Survey 18 | Question 2-6  Question 7-12  Question 13-15  Question 16-21  Question 22-42 |
| 8 | Have you ever had an injury to your head or neck due to the following? (Check all that apply) | 0🖵 No  1🖵 Childhood injuries  2🖵 Falling or being hit or playing sports  3🖵 Fights/Violence  4🖵 Car or moving vehicle  5🖵 Explosion/Blast  6🖵 Other  7🖵 Don’t know | Survey 14 (1) | Box Row 1  Box Row 3  Box Row 4  Box Row 2  Box Row 5 |
| 9 | Have you ever received any electrical shock that resulted in the following? (Check all that apply) | 0🖵 No  1🖵 Unconsciousness  2🖵 Burn  3🖵 Just the electrical shock  4🖵 Don’t know | Survey 14 (2) | Box Row 1  Box Row 2  Box Row 3 |
| 10 | What kind of health insurance or health care coverage do you have? Exclude private plans that only provide extra cash while hospitalized. If you have more than one kind of health insurance, please check the box next to each plan that you have. (Check all that apply) | 1🖵 HMO  2🖵 Private health insurance (non-HMO employer-sponsored)  3🖵 Medicare  4🖵 Medi- GAP (private insurance that supplements Medicare)  5🖵 Medicaid  6🖵 VA (Veteran’s Administration)  7🖵 Other military health care (CHAMP, TRICARE, Department of Defense health plans)  8🖵 Indian Health Service 9🖵 State-sponsored health plan  10🖵 Other government program (specify)  11🖵 Other health insurance plan: (specify)  12🖵 No health care coverage of any type  13🖵 Don’t know | Survey 15 |  |

## ENVIRONMENTAL FACTORS

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **EQ** | **Item** | **Responses** | **Origin** | **Follow-up** |
| 1 | What is your current employment status? | 1🖵 Full-time employed  2🖵 Part-time employed  3🖵 Retired  4🖵 Disabled  5🖵 Full-time student  6🖵 Homemaker  7🖵 Unemployed  8🖵 Other (specify) | Survey 2 | Question 2-5 |
| 2 | Were you ever a member of the armed forces? (Check all that apply) | 0🖵 No  1🖵 Army  2🖵 Navy  3🖵 Marines  4🖵 Air Force  5🖵 Reserves/National Guard  6🖵 Coast Guard  7🖵 Don’t know | Survey 3 |  |
| 3 | Were you ever deployed to a war arena? (Check all that apply) | 0🖵 No  1🖵 World War II  2🖵 Korean Conflict  3🖵 Vietnam War  4🖵 Persian Gulf  5🖵 Afghanistan War  6🖵 Persian Gulf II  7🖵 Other (specify) | Survey 3 |  |
| 4 | Over your lifetime (at least 100 days or more), have you ever had a **job** where you worked with the following **pesticides**? (Check all that apply) | 0🖵 No  1🖵 Herbicides  2🖵 Fungicides  3🖵 Insecticides  4🖵 Rodenticides  5🖵 Fumigants  6🖵 Don’t know | Survey 9 | Box Row 1  Box Row 2  Box Row 3  Box Row 4  Box Row 5 |
| 5 | Over your lifetime (at least 100 days or more), have you ever had a **job** where you were exposed to the following **chemicals**? (Check all that apply) | 0🖵 No  1🖵 Glues or adhesives  2🖵 Solvents and degreasers  3🖵 Unleaded gasoline  4🖵 Unleaded paint  5🖵 Formaldehyde  6🖵 Other chemicals (specify)  7🖵 Don’t know | Survey 9 | Box Row 6  Box Row 7  Box Row 8  Box Row 10  Box Row 12  Box Row 16 |
| 6 | Over your lifetime (at least 100 days or more), have you ever had a **job** where you were exposed to the following **metals/metal work**? (Check all that apply) | 0🖵 No  1🖵 Leaded gasoline  2🖵 Lead paint  3🖵 Soldering  4🖵 Welding/brazing/flame cutting  5🖵 Metal dust or fume  6🖵 Don’t know | Survey 9 | Box Row 9  Box Row 11  Box Row 13  Box Row 14  Box Row 15 |
| 7 | Have you ever personally handled any of the following outside work (such as home or garden) for a potential exposure to **pesticides**? (Check all that apply) | 0🖵 No  1🖵 Herbicides  2🖵 Fungicides  3🖵 Insecticides  4🖵 Gardening  5🖵 Don’t know | Survey 10  Survey 11 | Row 3  Row 4  Row 1 and 2  Box Row 9 |
| 8 | Have you ever personally handled any of the following outside work (such as home or garden) for a potential exposure to **chemicals**? (Check all that apply) | 0🖵 No  1🖵 Pet tick/flea treatment (soaps, shampoos, dips, or powder)  2🖵 Leatherwork  3🖵 Oil-based painting  4🖵 Woodworking  5🖵 Car repairing/restoring  6🖵 Using glue to build wooden/plastic models  7🖵 Developing photographs  8🖵 Don’t know | Survey 10  Survey 11 | Row 5  Box Row 1  Box Row 3  Box Row 5  Box Row 6  Box Row 7  Box Row 8 |
| 9 | Have you ever personally handled any of the following outside work (such as home or garden) for a potential exposure to **metals**? (Check all that apply) | 0🖵 No  1🖵 Glazing pottery/ceramics  2🖵 Remodeling/paint scraping on homes built before 1960  3🖵 Soldering, welding, metal work  4🖵 Outdoor hunting or shooting  5🖵 Indoor range gun shooting  6🖵 Bullet casting or reloading  7🖵 Fishing with lead weights/sinkers  8🖵 Knitting and jewelry making  9🖵 Other hobbies (specify)  10🖵 Don’t know | Survey 11 | Box Row 2  Box Row 4  Box Row 10  Box Row 11  Box Row 12  Box Row 13  Box Row 14  Box Row 15  Box Row 16 |
| 10 | To the best of your knowledge, have you ever lived for more than 6 months in areas with following environment? (Check all that apply) | 0🖵 No  1🖵 Farm or ranch  2🖵 Private well as source of water  3🖵 Within ¼ miles of agricultural area sprayed with pesticides/herbicides  6🖵 Don’t know | Survey 8 | Question 4🡪 1,2, 3  Question 5🡪 1,2, 3  Question 6/6a🡪 1,2, 3 |

## ALS-ASSOCIATED AND CLINICAL FACTORS

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **EQ** | **Item** | **Responses** | **Origin** | **Follow-up** |
| 1 | Has any member of your immediate biological family member diagnosed with ALS, Parkinson’s, or Alzheimer’s disease? (Check all that apply) | 0🖵 No  1🖵 Mother  2🖵 Father  3🖵 Sister  4🖵 Brother  5🖵 Children  6🖵 Don’t know | Survey 6 | Question M1-4  Question F1-4  Question 1, S1-4  Question 2, B1-4  Question 3, C1-5 |
| 2 | Compared with the time before you had symptoms of ALS or another motor neuron disease: have you noticed changes in the following? (Check all that apply) | 0🖵 No  1🖵 Speech  2🖵 Amount of saliva  3🖵 Swallowing  4🖵 Handwriting  5🖵 Ways of getting nutrition  6🖵 Cutting food and handling utensils  7🖵 Feeding tube use  8🖵 Getting dressed and performing self-care activities  9🖵 Turning in bed and adjusting bed sheet/blanket  10🖵 Walking  11🖵 Climbing stairs  12🖵 Breathing and shortness of breath  13🖵 Requiring respiratory support (BiPAP®)  14🖵 Don’t know | Survey 7 | Question 1  Question 2  Question 3  Question 4  Question 5  Question 6  Question 7  Question 8  Question 9  Question 10  Question 11  Question 12-13  Question 14 |
| 3 | In what part of the body did you first notice weakness that was diagnosed as ALS. (Check all that apply) | 0🖵 Not applicable  1🖵 Speech and or swallowing muscles  2🖵 Arm or hand  3🖵 Neck, back or abdominal area  4🖵 Leg or foot  5🖵 Breathing muscles  6🖵 All over my body  7🖵 Don’t know | Survey 17 | Question 1 (IF ANY) |
| 4 | Before you noticed weakness that turned out to be ALS, did you experience any of the following? (Check all that apply) | 0🖵 No  1🖵 Cramps or muscle spasm  2🖵 Scattered muscle twitching  3🖵 Difficulty swallowing  4🖵 Problems with speech  5🖵 Difficulty controlling bowels or bladder  6🖵 Don’t know | Survey 17 | Question 3  Box Row 1  Box Row 2  Box Row 3  Box Row 4  Box Row 5 |
| 5 | Have you ever used/had the following? (Check all that supply) | 0🖵 No  1🖵 Wheelchair/Electric scooter  2🖵 Breathing equipment (BiPap®)  3🖵 Tracheostomy  4🖵 Communication device  5🖵 Hospice program  6🖵 Don’t know | Survey 17 | Question 5  Box Row 1  Box Row 2  Box Row 3  Box Row 4  Box Row 5 |
| 6 | Since you developed ALS, have you had any of the following? (Check all that apply) | 0🖵 No  1🖵 Pneumonia  2🖵 Falls  3🖵 Blood clot  4🖵 Don’t know | Survey 17 | Question 6 |
| 7 | Have you taken the either riluzole (Rilutek®) and/or edaravone (Radicava®)? | 1🖵 Yes 🡪  2🖵 No  9🖵 Don’t know | Survey 17 | Question 4 |

**Greyed out items are questions already covered in the Essential Questionnaire**

# FOLLOW-UP QUESTIONS

## REGISTRATION

No follow up questions.

## DEMOGRAPHY

SURVEY 1

1. What is your date of birth? 🖵🖵 🖵🖵🖵🖵

Month Year

2. How old are you today? 🖵🖵 years old

3. How old were you when you were told by a neurologist that you had ALS? 🖵🖵 years old

4. What is your gender? 1🖵 Male 2🖵 Female

5. What is your current marital status?

1🖵 Never married 2🖵 Married 3🖵 Separated

4🖵 Divorced 5🖵 Widowed 6🖵 Living with partner

6. What is the highest level of education that you have completed?

1🖵 Did not complete High School – Specify highest grad completed 🖵🖵

2🖵 High school diploma or GED

3🖵 Technical or trade school diploma

4🖵 Some college credit

5🖵 College degree (AA, BA, BS, etc)

6🖵 Graduate school degree 7🖵 Other (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

7. Do you consider yourself Spanish, Hispanic, or Latino/Latina?

1🖵 No 2🖵 Yes, Puerto Rican

3🖵 Yes, Mexican, Mexican American, Chicano 4🖵 Yes, Cuban

5🖵 Yes, other Spanish, Hispanic, or Latino/Latina (specify):

8. What do you consider to be your race or ethnic group? If you belong to more than one of these groups, please indicate all groups that apply to you.

1🖵 White 2🖵 Black or African-American

3🖵 Native American or Alaska Native 4🖵 Asian Indian

5🖵 Chinese 6🖵 Filipino

7🖵 Japanese 8🖵 Korean

9🖵 Vietnamese 10🖵 Other Asian (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

11🖵 Native Hawaiian 12🖵 Guamanian or Chamorro

13🖵 Samoan 14🖵 Other Pacific Islander

(specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

99🖵 Don’t know

19. In what country were you born?

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

## LIFESTYLE INFORMATION

***We are now going to ask you to answer a few questions about your health-related lifestyle factors.***

SURVEY 1: BMI

10. What is your current height? 🖵 (ft) 🖵🖵 (in)

11. What is your current weight? 🖵🖵🖵 (lbs)

12. What was your height at age 40 years? 🖵 (ft) 🖵🖵 (in)

13. What was your weight at age 40 years? 🖵🖵🖵 (lbs)

SURVEY 4: SMOKING AND ALCOHOL

1. Have you ever smoked one or more cigarettes per day for six months or longer?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2**.** If yes, how old were you when you first started smoking one or more cigarettes per day? 🖵🖵 years old

3**.** Are you still a cigarette smoker?

1🖵 Yes 2🖵 No 9🖵 Don’t know

4**.** If no, at what age did you last stop smoking cigarettes?

🖵🖵 years old

5**.** During periods when you smoked, for how many years in total did you smoke cigarettes?

🖵🖵 years

6. During periods when you smoked, how many cigarettes did you usually smoke in a day? One pack contains 20 cigarettes.

🖵🖵 number cigarettes per day

**ALCOHOL**

7. Did you ever drink alcoholic beverages such as wine, beer and spirits at least once a month for 6 months or more?

1🖵 Yes 2🖵 No 9🖵 Don’t know

8**.** Are you still drinking alcoholic beverages at least once per month?

1🖵 Yes 2🖵 No

9. During periods when you were drinking alcoholic beverages, for how many years in total did you drink alcoholic beverages? 🖵🖵 years

10. During periods when you were drinking, how many alcoholic beverages did you usually havein a week ***OR*** month? A drink is 12 oz. beer, 4 ounces of wine or a drink containing 1 oz. of liquor. Please select week or month.

🖵🖵 number of drinks per 1🖵 week ***OR*** 2🖵 month

SURVEY 5: PHYSICAL ACTIVITY

1. Have you ever engaged in a routine that includes vigorous leisure-time physical activity for at least 10 minutes a day that caused heavy sweating or large increases in breathing or heart rate?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2**.** If yes, please indicate the number of times per week, month ***OR*** year that you engaged in vigorous activity for at least 10 minutes for each age period **(*up to your current age period)***.

|  |  |  |  |
| --- | --- | --- | --- |
| **Age period** | **Engaged in Physical Activity** | **Number of Times** | ***Please check one***  **Week Month Year** |
| 15-24 years | 1🖵 Yes 2🖵 No | 🖵🖵 | 1🖵 2🖵 3🖵 |
| 25-34 years | 1🖵 Yes 2🖵 No 3🖵 Age not applicable | 🖵🖵 | 1🖵 2🖵 3🖵 |
| 35-44 years | 1🖵 Yes 2🖵 No 3🖵 Age not applicable | 🖵🖵 | 1🖵 2🖵 3🖵 |
| 45-54 years | 1🖵 Yes 2🖵 No 3🖵 Age not applicable | 🖵🖵 | 1🖵 2🖵 3🖵 |
| 55-64 years | 1🖵 Yes 2🖵 No 3🖵 Age not applicable | 🖵🖵 | 1🖵 2🖵 3🖵 |
| 65 years or older | 1🖵 Yes 2🖵 No 3🖵 Age not applicable | 🖵🖵 | 1🖵 2🖵 3🖵 |

SURVEY 13: CAFFEINE

***The next questions pertain to your usual caffeine habits as an adult. By usual, we mean drinking the beverage at least once a month for six months or more.***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Did you ever drink espresso or espresso drinks (Latte, Mocha, Americano)? A serving of espresso is 1 shot.    1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** drink espresso or espresso drinks at least once per month?  Age 🖵🖵 | Are you still drinking espresso or espresso drinks at least once per month?  1🖵 Yes  2🖵 No 🡺  9🖵 Don’t know | **If no**, at what age did you **LAST** drink espresso or espresso drinks at least once per month?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. Were there any periods of time during these \_\_ \_\_ years when you did **NOT** drink espresso or espresso drinks? If no, then record as 00 years).  🖵🖵 Years | During the periods when you did drink espresso, how often (per day, week, month **or** year) did you drink them?  🖵🖵 number of drinks per  ***Please check one***  1🖵 day **OR** 2🖵 week **OR**  3🖵 month **OR** 4🖵 year |
| Did you ever drink caffeinated coffee? A serving of coffee is 8 ounces.     1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** drink caffeinated coffee at least once per month?  Age 🖵🖵 | Are you still drinking caffeinated coffee at least once per month?  1🖵 Yes  2🖵 No 🡺  9🖵 Don’t know | **If no**, at what age did you **LAST** drink caffeinated coffee at least once per month?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** drink caffeinated coffee?  🖵🖵 Years | During the periods when you did drink caffeinated coffee, how often (per day, week, month **or** year) did you drink it?  🖵🖵 number of drinks per  ***Please check one***  1🖵 day **OR** 2🖵 week **OR**  3🖵 month **OR** 4🖵 year |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Did you ever drink caffeinated tea (green or black), hot or iced? A serving of tea is 8 oz.     1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** drink caffeinated tea at least once per month?  Age 🖵🖵 | Are you still drinking caffeinated tea at least once per month?  1🖵 Yes  2🖵 No 🡺  9🖵 Don’t know | **If no**, at what age did you **LAST** drink caffeinated tea at least once per month?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** drink caffeinated tea?  🖵🖵 Years | During the periods when you did drink caffeinated tea, how often (per day, week, month **or** year) did you drink them?  🖵🖵 number of drinks per  ***Please check one***  1🖵 day **OR** 2🖵 week **OR**  3🖵 month **OR** 4🖵 year |
| Did you ever drink highly caffeinated drinks, including Jolt®, Surge®, Mountain Dew MDX®, Red Bull®? A serving of these drinks is a 12 oz can.   1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** drink highly caffeinated drinks at least once per month?  Age 🖵🖵 | Are you still drinking highly caffeinated drinks at least once per month?  1🖵 Yes  2🖵 No 🡺  9🖵 Don’t know | **If no**, at what age did you **LAST** drink highly caffeinated drinks at least once per month?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** drink highly caffeinated drinks?  🖵🖵 Years | During the periods when you did drink highly caffeinated drinks, how often (per day, week, month **or** year) did you drink them?  1🖵🖵 number of drinks per  ***Please check one***  1🖵 day **OR** 2🖵 week **OR**  3🖵 month **OR** 4🖵 year |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Did you ever drink caffeinated soda, including colas, Barq’s Root Beer ® or regular Mountain Dew®? A serving of colas or root beer is a 12 oz can.   1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** drink caffeinated soda at least once per month?  Age 🖵🖵 | Are you still drinking caffeinated soda at least once per month?  1🖵 Yes  2🖵 No 🡺  9🖵 Don’t know | **If no**, at what age did you **LAST** drink caffeinated soda at least once per month?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** drink caffeinated soda?  🖵🖵 Years | During the periods when you did drink caffeinated soda, how often (per day, week, month **or** year) did you drink them?  🖵🖵 number of drinks per  ***Please check one***  1🖵 day **OR** 2🖵 week **OR**  3🖵 month **OR** 4🖵 year |

SURVEY 14: TRAUMA

**HEAD and NECK INJURIES**

***The next questions are about injuries to your head and/or neck that that you may have had at anytime in your life. These may have occurred during sporting activities, from falls, violence, car accidents or other accidents. Please include injuries from both childhood and adulthood.***

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Have you ever had an injury to your head or neck? Think about any childhood injuries you remember or were told about.  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many head or neck injuries have you had?     Num. 🖵🖵 | At what age did the **FIRST** injury occur?  Age 🖵🖵 | Did you lose consciousness from this injury?      1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How long were you unconscious?    1🖵 Less than 5 minutes  2🖵 5-59 minutes  3🖵 1-24 hours  4🖵 Longer than a day  9🖵 Don’t know | Did you go to the emergency room or were you hospitalized for this injury?   1🖵 Yes  2🖵 No  9🖵 Don’t know | From this injury, did you have any of the following (check all that apply)?    1🖵 Skull fracture  2🖵 Seizure  3🖵 Memory loss, amnesia  4🖵 None of the above  9🖵 Don’t know |
| Have you ever injured your head or neck in a car accident or from some other moving vehicle accident (e.g. motorcycle, ATV)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many accidents have you had?     Num. 🖵🖵 | At what age did the **FIRST** accident occur?  Age 🖵🖵 | Did you lose consciousness from this accident?      1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How long were you unconscious?   1🖵 Less than 5 minutes  2🖵 5-59 minutes  3🖵 1-24 hours  4🖵 Longer than a day  9🖵 Don’t know | Did you go to the emergency room or were you hospitalized for this injury?   1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | From this injury, did you have any of the following (check all that apply)?    1🖵 Skull fracture  2🖵 Seizure  3🖵 Memory loss, amnesia  4🖵 None of the above  9🖵 Don’t know |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Have you ever injured your head or neck in a fall or from being hit by something (e.g., falling from a bike, horse, or rollerblades, falling on ice, being hit by a rock)? Have you ever injured your head or neck playing sports or on the playground?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many head or neck injuries from a fall or being hit by something have you had?       Num. 🖵🖵 | At what age did the **FIRST** head or neck injury from a fall or being hit by something occur?  Age 🖵🖵 | Did you lose consciousness from this injury?             1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How long were you unconscious?          1🖵 Less than 5 minutes  2🖵 5-59 minutes  3🖵 1-24 hours  4🖵 Longer than a day  9🖵 Don’t know | Did you go to the emergency room or were you hospitalized for this injury?          1🖵 Yes  2🖵 No  9🖵 Don’t know | From this injury, did you have any of the following (check all that apply)?           1🖵 Skull fracture  2🖵 Seizure  3🖵 Memory loss, amnesia  4🖵 None of the above  9🖵 Don’t know |
| Have you ever injured your head or neck in a fight, from being hit by someone, or from being shaken violently? Have you ever been shot in the head?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many head or neck injuries have you had in a fight or from other violence?     Num. 🖵🖵 | At what age did the **FIRST** head or neck injury in a fight or from other violence occur?  Age 🖵🖵 | Did you lose consciousness from this injury?        1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How long were you unconscious?     1🖵 Less than 5 minutes  2🖵 5-59 minutes  3🖵 1-24 hours  4🖵 Longer than a day  9🖵 Don’t know | Did you go to the emergency room or were you hospitalized for this injury?      1🖵 Yes  2🖵 No  9🖵 Don’t know | From this injury, did you have any of the following (check all that apply)?      1🖵 Skull fracture  2🖵 Seizure  3🖵 Memory loss, amnesia  4🖵 None of the above  9🖵 Don’t know |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Have you ever been nearby when an explosion or blast occurred? If you served in the military, think about any combat, or training related incidents?   1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many times were you near an explosion or blast?    Num. 🖵🖵 | At what age did the **FIRST** head or neck injury from an explosion or blast occur?  Age 🖵🖵 | Did you lose consciousness from this injury?        1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How long were you unconscious?     1🖵 Less than 5 minutes  2🖵 5-59 minutes  3🖵 1-24 hours  4🖵 Longer than a day  9🖵 Don’t know | Did you go to the emergency room or were you hospitalized for this injury?      1🖵 Yes  2🖵 No  9🖵 Don’t know | From this injury, did you have any of the following (check all that apply)?      1🖵 Skull fracture  2🖵 Seizure  3🖵 Memory loss, amnesia  4🖵 None of the above  9🖵 Don’t know |

**ELECTRICAL SHOCKS**

|  |  |  |
| --- | --- | --- |
| Have you ever received a severe electrical shock that resulted in unconsciousness?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many shocks of this type have you received?    Number of times 🖵🖵 | At what age did you **FIRST** receive a shock that resulted in unconsciousness?  Age 🖵🖵 |
| Have you ever received a severe electrical shock that resulted in a burn?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many shocks of this type have you received?    Number of times 🖵🖵 | At what age did you **FIRST** receive a shock that resulted in a burn?  Age 🖵🖵 |
| Have you ever received a severe electrical shock that did not result in unconsciousness or a burn?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many shocks of this type have you received?  Number of times 🖵🖵 | At what age did you **FIRST** receive a shock that did not result in unconsciousness or a burn?  Age 🖵🖵 |

SURVEY 15: HEALTH INSURANCE

What kind of health insurance or health care coverage do you have? Exclude private plans that only provide extra cash while hospitalized. If you have more than one kind of health insurance, please check the box next to each plan that you have.

Please mark all that apply

HMO 1🖵

Private health insurance (non-HMO employer-sponsored) 2🖵

MEDICARE 3🖵

MEDI-GAP (private insurance that supplements Medicare) 4🖵

MEDICAID 5🖵

VA (Veteran’s Administration) 6🖵

Other military health care (CHAMP, TRICARE, Department of Defense health plans) 7🖵

Indian Health Service 8🖵

State-sponsored health plan 9🖵

Other government program (specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_) 10🖵

Other health insurance plan: (specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_) 13🖵

No health care coverage of any type 11🖵

Don’t know 12🖵

## EVIRONMENTAL FACTORS

SURVEY 2: OCCUPATION

1. What is your current employment status?

1🖵 Full-time employed 2🖵 Part-time employed

3🖵 Retired 4🖵 Disabled

5🖵 Full-time student 6🖵 Homemaker

7🖵 Unemployed 8🖵 Other (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

2. If currently employed, what is your occupation? ***Please indicate your job title and the industry in which you work***.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

JOB TITLE

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

INDUSTRY

3**.** For how many years have you been employed in this occupation? 🖵🖵 years

4. Thinking about your entire working career, in which job were you employed for the longest period of time? ***Please indicate your job title, occupation, and the industry in which you worked***.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

JOB TITLE

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

INDUSTRY

5**.** For how many years were you employed in this occupation? 🖵🖵 years

SURVEY 3: MILITARY HISTORY

1. Were you ever a member of the armed forces?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2. If yes, in which branch of service were you employed?

1🖵 Army 2🖵 Navy 3🖵 Marines

4🖵 Air Force 5🖵 Reserves/National Guard 6🖵 Coast Guard

3. Were you ever deployed to a war arena?

1🖵 Yes 2🖵 No

4. If yes, to which war arena were you deployed?

1🖵 World War II 2🖵 Korean Conflict

3🖵 Vietnam War 4🖵 Persian Gulf

5🖵 Afghanistan War 6🖵 Persian Gulf II

7🖵 Other (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

SURVEY 8: RESIDENCE HISTORY

***We are interested in the location of your residences for all the places where you lived for a period of 6 months or longer. Starting with the place where you were born, indicate the city and state (or country) of each place where you lived for 6 months or longer. If you lived on a farm, please give the nearest city or town. If you moved to a different residence within the same city, please include each home or dwelling as a separate entry.***

Helpful Hint: Consider making a list of places you have lived before you start this survey.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 1. At what age did you move to your next residence of **6 months or longer**? | 2. In what city or town was this residence? | 3. In what state (or country) was this residence? | 4. Was this residence a farm or a ranch? | 5. Was your main source of drinking water at this residence a private well? | 6. Was this residence within **¼ mile** of an agricultural area that was sprayed with pesticides or herbicides? | 6a. **IF YES**  How often did the pesticide or herbicide spraying happen? |
| BIRTH | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_ | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 < 1 time/year  2🖵 1-3 times/year  3🖵 > 4 times/year  9🖵 Don’t know |
| AFTER EVERY RESIDENCE ASK: Was this your current or most recent residence? 1🖵 Yes 2🖵 No (if no go to Next Residence) | | | | | | |
| 🖵🖵 years old | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_ | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 < 1 time/year  2🖵 1-3 times/year  3🖵 > 4 times/year  9🖵 Don’t know |
| 🖵🖵 years old | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_ | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 < 1 time/year  2🖵 1-3 times/year  3🖵 > 4 times/year  9🖵 Don’t know |
| 🖵🖵 years old | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_ | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 < 1 time/year  2🖵 1-3 times/year  3🖵 > 4 times/year  9🖵 Don’t know |
| 🖵🖵 years old | \_\_\_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_\_\_\_ | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 Yes  2🖵 No  9🖵 Don’t know | 1🖵 < 1 time/year  2🖵 1-3 times/year  3🖵 > 4 times/year  9🖵 Don’t know |

SURVEY 9: LIFETIME OCCUPATIONAL HISTORY

***The following questions ask about pesticides or chemicals that you may have used at work during at least 100 days or more during your lifetime.***

**PESTICIDES**

***We are interested in those pesticide products that you personally handled on the JOB, either by preparing them prior to application, by applying them yourself or by helping to clean up after they were applied.***

|  |  |  |  |
| --- | --- | --- | --- |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled HERBICIDES (to kill weeds)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** handle herbicides?  Age 🖵🖵 | At what age did you **LAST** handle herbicides?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use herbicides?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled FUNGICIDES (to control mildew, mold or rot)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** handle fungicides?  Age 🖵🖵 | At what age did you **LAST** handle fungicides?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use fungicides?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled INSECTICIDES (to control insects or pests)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** handle insecticides?  Age 🖵🖵 | At what age did you **LAST** handle insecticides?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use insecticides?  Years 🖵🖵 |

|  |  |  |  |
| --- | --- | --- | --- |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled RODENTICIDES (to kill rats or mice)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** handle rodenticides?  Age 🖵🖵 | At what age did you **LAST** handle rodenticides?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use rodenticides?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you handled FUMIGANTS (gas used to kill fungus, mold or insects)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** handle fumigants?  Age 🖵🖵 | At what age did you **LAST** handle fumigants?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use fumigants?  Years 🖵🖵 |

**SOLVENTS**

|  |  |  |  |
| --- | --- | --- | --- |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you used GLUES OR ADHESIVES?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** use glues or adhesives?  Age 🖵🖵 | At what age did you **LAST** use glues or adhesives?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use glues or adhesives?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you used SOLVENTS AND DEGREASERS?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** use solvents and degreasers?  Age 🖵🖵 | At what age did you **LAST** use solvents and degreasers?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use solvents and degreasers?  Years 🖵🖵 |

|  |  |  |  |
| --- | --- | --- | --- |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with UNLEADED GASOLINE?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** work with unleaded gasoline?  Age 🖵🖵 | At what age did you **LAST** work with unleaded gasoline?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use unleaded gasoline?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with LEADED GASOLINE?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** work with leaded gasoline?  Age 🖵🖵 | At what age did you **LAST** work with leaded gasoline?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use leaded gasoline?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you used UNLEADED PAINT?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** use unleaded paint?  Age 🖵🖵 | At what age did you **LAST** use unleaded paint?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years For how many of those years did you **NOT** use unleaded paint?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you used LEADED PAINT?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** use leaded paint?  Age 🖵🖵 | At what age did you **LAST** use leaded paint?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use leaded paint?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you used FORMALDEHYDE?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** use formaldehyde?  Age 🖵🖵 | At what age did you **LAST** use formaldehyde?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use formaldehyde?  Years 🖵🖵 |

**METALS**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you SOLDERED?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** solder?    Age 🖵🖵 | At what age did you **LAST** solder?    Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** solder?  Years 🖵🖵 | What specific metals or materials did you solder?  Tin: 1🖵 Yes 2🖵 No 9🖵 Don’t know  Silver: 1🖵 Yes 2🖵 No 9🖵 Don’t know  Other metals or alloy: 1🖵 Yes 2🖵 No 9🖵 Don’t know  **IF OTHER**: Specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you WELDED, BRAZED OR FLAME CUT METALS?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** weld, braze or flame cut metals?    Age 🖵🖵 | At what age did you **LAST** weld, braze or flame cut metals?    Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** weld, braze or flame cut metals?  Years 🖵🖵 | What specific metals or materials did you weld, braze or flame cut?  Steel: 1🖵 Yes 2🖵 No 9🖵 Don’t know  Iron, copper or aluminum 1🖵 Yes 2🖵 No 9🖵 Don’t know  Brass or bronze 1🖵 Yes 2🖵 No 9🖵 Don’t know  Lead 1🖵 Yes 2🖵 No 9🖵 Don’t know  Other metals or alloy: 1🖵 Yes 2🖵 No 9🖵 Don’t know  **IF OTHER**: Specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you were exposed to METAL DUST OR METAL FUMES?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age were you **FIRST** exposed to metal dust of metal fumes?  Age 🖵🖵 | At what age were you **LAST** exposed to metal dust of metal fumes?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years were you **NOT** exposed to metal dust of metal fumes?  Years 🖵🖵 | To which specific metal dust or metal fumes were you exposed?  Steel: 1🖵 Yes 2🖵 No 9🖵 Don’t know  Iron, copper or aluminum 1🖵 Yes 2🖵 No 9🖵 Don’t know  Brass or bronze 1🖵 Yes 2🖵 No 9🖵 Don’t know  Lead 1🖵 Yes 2🖵 No 9🖵 Don’t know  Other metals or alloy: 1🖵 Yes 2🖵 No 9🖵 Don’t know  **IF OTHER**: Specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

**OTHER OCCUPATIONAL EXPOSURE**

|  |  |  |  |
| --- | --- | --- | --- |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know  IF YES:  Please specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | At what age did you **FIRST** work with this chemical?  Age 🖵🖵 | At what age did you **LAST** work with this chemical?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use this chemical?  Years 🖵🖵 |
| Over your lifetime (at least 100 days or more), have you ever had a JOB where you worked with ANY OTHER CHEMICAL?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know  IF YES:  Please specify:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | At what age did you **FIRST** work with this chemical?  Age 🖵🖵 | At what age did you **LAST** work with this chemical?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** use this chemical?  Years 🖵🖵 |

SURVEY 10: HOME PESTICIDE USE

***The following questions are about chemicals or home pesticides that you used to kill insects, plants, weeds, mold or mildew, or other pests in or around any house or apartment where you lived. We are interested only in those products that you personally handled, either by preparing them prior to application, by applying them yourself, or by helping to clean up after they were applied. Please consider products that you have personally handled at any time in your life.***

***Please consider only the time from 10 years of age to the present.***

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Have you ever personally handled insecticides to control insects and pests in your home?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **first** handle insecticides in the home?  Age 🖵🖵 | At what age did you **last** handle insecticides in the home?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **not** handle insecticides in your home?  Age 🖵🖵 | During the periods when you did use insecticides in the home, how many days per year did you use them?  🖵🖵🖵 days per year |
| Have you ever personally handled insecticides to control insects and pests in your lawn or garden?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **first** handle insecticides in the lawn or garden?  Age 🖵🖵 | At what age did you **last** handle insecticides in the lawn or garden?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **not** handle insecticides in the lawn or garden?  Age 🖵🖵 | During the periods when you did use insecticides in the lawn or garden, how many days per year did you use them?  🖵🖵🖵 days per year |
| Have you ever used herbicides or weed killers to control weeds or plants in your lawn, garden, or other areas around the home?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **first** handle herbicides in the lawn or garden?  Age 🖵🖵 | At what age did you **last** handle herbicides in the lawn or garden?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **not** use herbicides in the lawn or garden?  Age 🖵🖵 | During the periods when you did use herbicides in the lawn or garden, how many days per year did you use them?  🖵🖵🖵 days per year |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Have you ever used fungicides to control mildew or rot in your home or plant mold in the garden?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **first** handle fungicides in the home or garden?  Age 🖵🖵 | At what age did you **last** handle fungicides in the home or garden?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **not** use fungicides?  Age 🖵🖵 | During the periods when you did use fungicides in the home or garden, how many days per year did you use them?  🖵🖵🖵 days per year |
| Have you ever personally applied chemical soaps, shampoos, dips or powders to kill fleas, ticks or other insects on a pet, such as a dog or a cat?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **first** apply these substances to your pet(s)?  Age 🖵🖵 | At what age did you **last** apply these substances to your pet(s)?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **not** apply these substances to your pets?  Age 🖵🖵 | During the periods when you did use these substances, how many days per year did you apply them to your pet(s)?  🖵🖵🖵 days per year |

SURVEY 11: HOBBIES

***The following questions are about home activities and hobbies you have performed on a regular basis, that is, for at least one hour each month for at least one year or more. Please consider only the time from when you were 10 years old to the present.***

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Have you ever done leather work (such as making belts, purses etc.)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do leather work?  Age 🖵🖵 | At what age did you **LAST** do leather work?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do leather work?  Years 🖵🖵 | During the period when you did leather work, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever lead glazed pottery or other ceramics?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** glaze pottery or other ceramics?  Age 🖵🖵 | At what age did you **LAST** glaze pottery or other ceramics?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** glaze pottery or other ceramics?  Years 🖵🖵 | During the period when you did glaze pottery or other ceramics, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever painted pictures or furniture with oil-based paint?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** paint pictures or furniture with oil-based paint?  Age 🖵🖵 | At what age did you **LAST** paint pictures or furniture with oil-based paint?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** paint pictures or furniture with oil-based paint?  Years 🖵🖵 | During the period when you did paint pictures or furniture with oil-based paint, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever done home remodeling projects that involved scraping, stripping, burning and sanding paint? Please count only houses built before 1960.  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960?  Age 🖵🖵 | At what age did you **LAST** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960?  Years 🖵🖵 | During the period when you did home remodeling projects that involved scraping, stripping, burning and sanding paint on houses built before 1960, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Have you ever done woodworking?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do woodworking?  Age 🖵🖵 | At what age did you **LAST** do woodworking?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do woodworking?  Years 🖵🖵 | During the period when you did woodworking, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever painted, repaired or restored old cars, other than fixing a flat tire or changing oil?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** paint,repair or restore old cars, other than fixing a flat tire or changing oil?  Age 🖵🖵 | At what age did you **LAST** paint,repair or restore old cars, other than fixing a flat tire or changing oil?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** paint,repair or restore old cars, other than fixing a flat tire or changing oil?  Years 🖵🖵 | During the period when you did paint,repair or restore old cars, other than fixing a flat tire or changing oil, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever built wooden or plastic models using glue?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** build wooden or plastic models using glue?  Age 🖵🖵 | At what age did you **LAST** build wooden or plastic models using glue?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** build wooden or plastic models using glue?  Years 🖵🖵 | During the period when you did build wooden or plastic models using glue, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever developed photographs?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** develop photographs?  Age 🖵🖵 | At what age did you **LAST** develop photographs?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** develop photographs?  Years 🖵🖵 | During the period when you did develop photographs, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever done gardening?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do gardening?  Age 🖵🖵 | At what age did you **LAST** do gardening?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do gardening?  Years 🖵🖵 | During the period when you did gardening, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Have you done soldering, welding, or metal work (such as sculpting, garden structures, etc.)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you FIRST solder, weld, or do metal work?  Age 🖵🖵 | At what age did you **LAST** solder, weld, or do metal work?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** solder, weld, or do metal work?  Years 🖵🖵 | During the period when you did solder, weld, or do metal work, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever done outdoor hunting or shooting with guns, including animals, skeet, trap or targets?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do outdoor hunting or shooting with guns, including animals, skeet, trap or targets?  Age 🖵🖵 | At what age did you **LAST** do outdoor hunting or shooting with guns, including animals, skeet, trap or targets?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do outdoor hunting or shooting with guns, including animals, skeet, trap or targets?  Years 🖵🖵 | During the period when you did outdoor hunting or shooting with guns, including animals, skeet, trap or targets, how many **hours each** **year** did you perform the activity?  🖵🖵 hours/year |
| Have you ever done gun shooting in an indoor pistol or rifle range?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do gun shooting in an indoor pistol or rifle range?  Age 🖵🖵 | At what age did you **LAST** do gun shooting in an indoor pistol or rifle range?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do gun shooting in an indoor pistol or rifle range?  Years 🖵🖵 | During the period when you did gun shooting in an indoor pistol or rifle range, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever done casting of bullets or reloading of ammunition?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do casting of bullets or reloading of ammunition?  Age 🖵🖵 | At what age did you **LAST** do casting of bullets or reloading of ammunition?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do casting of bullets or reloading of ammunition?  Years 🖵🖵 | During the period when you did casting of bullets or reloading of ammunition, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Have you ever done fishing using lead weights or sinkers?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | At what age did you **FIRST** do fishing using lead weights or sinkers?  Age 🖵🖵 | At what age did you **LAST** do fishing using lead weights or sinkers?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do fishing using lead weights or sinkers?  Years 🖵🖵 | During the period when you did fishing using lead weights or sinkers, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever done any other HOBBY, such as knitting, making jewelry? Please DO NOT consider physical activity, electronic games, writing as hobbies.  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know  If Yes, please specify hobby:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | At what age did you **FIRST** do this HOBBY?  Age 🖵🖵 | At what age did you **LAST** do this HOBBY?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do this HOBBY?  Years 🖵🖵 | During the period when you did this HOBBY, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |
| Have you ever done any other HOBBY such as knitting, making jewelry? Please DO NOT consider physical activity, electronic games, writing as hobbies.  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know  If Yes, please specify hobby:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | At what age did you **FIRST** do this HOBBY?  Age 🖵🖵 | At what age did you **LAST** do this HOBBY?  Age 🖵🖵 | This is a total of ***\_\_ \_\_*** years. For how many of those years did you **NOT** do this HOBBY?  Years 🖵🖵 | During the period when you did this HOBBY, how many **hours each** **month** did you perform the activity?  🖵🖵 hours/month |

SURVEY 12: HORMONAL AND REPRODUCTIVE HISTORY (WOMEN ONLY)

***The following questions are about your menstrual periods.***

|  |  |  |  |
| --- | --- | --- | --- |
| **How old were you when you had your first menstrual period?**    Age 🖵🖵 | **Have you had at least one menstrual period in the past 12 months? Please do not include bleedings caused by medical conditions, hormone therapy, or surgeries.**  1🖵 Yes  2🖵 No 🡺  9🖵 Don’t know | **IF NO**  What is the reason that you have **not had a period** in the past 12 months?  1🖵 Pregnancy  2🖵 Breast feeding  3🖵 Menopause/Hysterectomy  4🖵 Medical conditions/Treatments  5🖵 Other: Please specify  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  9🖵 Don’t know | How old were you when you had your **LAST** menstrual period?  Age 🖵🖵 |

***The next questions are about your pregnancy and childbirth history.***

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Have you ever been pregnant?**     1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  How many times have you been pregnant? Please count all pregnancies including, live births, miscarriages, stillbirths, tubal pregnancies or abortions)  Number of pregnancies 🖵🖵 | Are you currently pregnant?     1🖵 Yes  2🖵 No  9🖵 Don’t know | How many deliveries resulted in a live birth?  Number of live births 🖵🖵 | How old were you at the time of your **FIRST** live birth?  Age 🖵🖵 | How old were you at the time of your **LAST** live birth?  Age 🖵🖵 |

SURVEY 18: SPORTS HISTORY

|  |  |  |  |
| --- | --- | --- | --- |
| SPORTS SURVEY | | | |
| **1. Have you ever participated in organized sports?**  1 Yes  2 No  9 Don’t know    If No or Don’t know, **END** **survey** | NOTE: **Organized sports** are those that are played within a school or league setting. This does not include casual playing at home or in your community. |  |  |
| ORGANIZED FOOTBALL: Q2-Q6 | | | |
| **2. Did you play organized football?**  1 Yes **🡪**  2 No  9 Don’t know    If No or Don’t know, **skip to Question 7** | 2a. At what age did you **FIRST** start playing football?  Age | 2b. At what age did you **LAST** play football?  Age |  |
| **3. Did you play football professionally or semi-professionally?**  (**Note:** this does not include college football)  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 4** | 3a. At what age did you **FIRST** start playing professional or semi-professional football?  Age | 3b. At what age did you **LAST** play professional or semi-professional football?  Age | 3c. In what league did you play while playing football professionally or semi-professionally?  **(Select all that apply)**  1 NFL  2 AFL  3 CFL  4 NFL Europe  5 Arena League  6 XFL  7 Other: \_\_\_\_\_\_\_\_\_  9 Don’t know  \*Specify other |

|  |  |  |  |
| --- | --- | --- | --- |
| 3d. While playing professional or semi-professional football what did you play?  1 Offense  2 Defense  3 Special Teams  9 Don’t know  If Don’t know, **skip to Question 4** | 3di. Answer if you played an **OFFENSIVE** position.  What primary offensive position did you play while playing professional or semi-professional football?  1 Tackle  2 Guard  3 Center  4 Tight End  5 Other Offensive  Linemen  6 Quarterback  7 Half Back  8 Full Back  9 Running Back  10 Slot Back  11 Wide Receiver  12 Other:\_\_\_\_\_\_\_\_\_  99 Don’t know    \*Specify other | 3dii. Answer if you played a **DEFENSIVE** position.  What primary defensive position did you play while playing professional or semi-professional football?  1 Defensive Tackle  2 Defensive Guard  3 Nose Guard  4 Nose Tackle  5 Other Defensive  Linemen  6 Middle Linebacker  7 Strong Side  Linebacker  8 Weak Side  Linebacker  9 Outside  Linebacker  10 Other Linebacker  11 Cornerback  12 Safety  13 Strong Safety  14 Free Safety  15 Other Defensive  Back  16 Other:\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | 3diii. Answer if you played a **SPECIAL TEAMS** position.  What primary special teams position did you play while playing professional or semi-professional football?  1 Punter  2 Kicker  3 Kick Returner  4 Gunner  5 Wedge Buster  6 Return Blocker  7 Kick Coverage  8 FT/PAT Lineman  9 Other: \_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other |

|  |  |  |  |
| --- | --- | --- | --- |
| **4. Did you play football in college?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 5** | 4a. At what age did you **FIRST** start playing college football?  Age | 4b. At what age did you **LAST** college football?  Age | 4c. In what league did you play while playing college football?  **(Select all that apply)**  1 Division I/FBS  2 Division II/FCS  3 Division II  4 Division III  5 NAIA  6 Other: \_\_\_\_\_\_\_\_  9 Don’t know  \*Specify other |
| 4d. While playing college football what did you play?  1 Offense  2 Defense  3 Special Teams  9 Don’t know  If Don’t know, **skip to Question 5** | 4di. Answer if you played an **OFFENSIVE** position.  What primary offensive position did you play while playing college football?  1 Tackle  2 Guard  3 Center  4 Tight End  5 Other Offensive  Linemen  6 Quarterback  7 Half Back  8 Full Back  9 Running Back  10 Slot Back  11 Wide Receiver  12 Other:\_\_\_\_\_\_\_\_\_  9 Don’t know    \*Specify other | 4dii. Answer if you played a **DEFENSIVE** position.  What primary defensive position did you play while playing college football?  1 Defensive Tackle  2 Defensive Guard  3 Nose Guard  4 Nose Tackle  5 Other Defensive  Linemen  6 Middle Linebacker  7 Strong Side  Linebacker  8 Weak Side  Linebacker  9 Outside  Linebacker  10 Other Linebacker  11 Cornerback  12 Safety  13 Strong Safety  14 Free Safety  15 Other Defensive  Back  16 Other:\_\_\_\_\_\_\_\_\_  9 Don’t know  \*Specify other | 4diii. Answer if you played a **SPECIAL TEAMS** position.  What primary special teams position did you play while playing college football?  1 Punter  2 Kicker  3 Kick Returner  4 Gunner  5 Wedge Buster  6 Return Blocker  7 Kick Coverage  8 FT/PAT Lineman  9 Other: \_\_\_\_\_\_\_\_\_  9 Don’t know  \*Specify other |
| **5. Did you play football in high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 6** | 5a. At what age did you **FIRST** start playing high school football?  Age | 5b. At what age did you **LAST** high school football?  Age |  |
| 5c. While playing high school football what did you play?  1 Offense  2 Defense  3 Special Teams  9 Don’t know  If Don’t know, **skip to Question 6** | 5ci. Answer if you played an **OFFENSIVE** position.  What primary offensive position did you play while playing high school football?  1 Tackle  2 Guard  3 Center  4 Tight End  5 Other Offensive  Linemen  6 Quarterback  7 Half Back  8 Full Back  9 Running Back  10 Slot Back  11 Wide Receiver  12 Other:\_\_\_\_\_\_\_\_\_  99 Don’t know    \*Specify other | 5cii. Answer if you played a **DEFENSIVE** position.  What primary defensive position did you play while playing high school football?  1 Defensive Tackle  2 Defensive Guard  3 Nose Guard  4 Nose Tackle  5 Other Defensive  Linemen  6 Middle Linebacker  7 Strong Side  Linebacker  8 Weak Side  Linebacker  9 Outside  Linebacker  10 Other Linebacker  11 Cornerback  12 Safety  13 Strong Safety  14 Free Safety  15 Other Defensive  Back  16 Other:\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | 5ciii. Answer if you played a **SPECIAL TEAMS** position.  What primary special teams position did you play while playing high school football?  1 Punter  2 Kicker  3 Kick Returner  4 Gunner  5 Wedge Buster  6 Return Blocker  7 Kick Coverage  8 FT/PAT Lineman  9 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other |

|  |  |  |  |
| --- | --- | --- | --- |
| **6. Did you play football prior to high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 7** | 6a. At what age did you **FIRST** start playing football prior to high school?  Age | 6b. At what age did you **LAST** start playing football prior to high school?  Age |  |
| 6c. While playing football prior to high school what did you play?  1 Offense  2 Defense  3 Special Teams  9 Don’t know  If Don’t know, **skip to Question 7** | 6ci. Answer if you played an **OFFENSIVE** position.  What primary offensive position did you play while playing high school football?  1 Tackle  2 Guard  3 Center  4 Tight End  5 Other Offensive  Linemen  6 Quarterback  7 Half Back  8 Full Back  9 Running Back  10 Slot Back  11 Wide Receiver  12 Other:\_\_\_\_\_\_\_\_\_  99 Don’t know    \*Specify other | 6cii. Answer if you played a **DEFENSIVE** position.  What primary defensive position did you play while playing high school football?  1 Defensive Tackle  2 Defensive Guard  3 Nose Guard  4 Nose Tackle  5 Other Defensive  Linemen  6 Middle Linebacker  7 Strong Side  Linebacker  8 Weak Side  Linebacker  9 Outside  Linebacker  10 Other Linebacker  11 Cornerback  12 Safety  13 Strong Safety  14 Free Safety  15 Other Defensive  Back  16 Other:\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | 6ciii. Answer if you played a **SPECIAL TEAMS** position.  What primary special teams position did you play while playing high school football?  1 Punter  2 Kicker  3 Kick Returner  4 Gunner  5 Wedge Buster  6 Return Blocker  7 Kick Coverage  8 FT/PAT Lineman  9 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other |

|  |  |  |  |
| --- | --- | --- | --- |
| ORGANIZED HOCKEY: Q7-Q12 | | | |
| **7. Did you play organized hockey?**  1 Yes **🡪**  2 No  9 Don’t know    If No or Don’t know, **skip to Question 14** | 7a. At what age did you **FIRST** start playing hockey?  Age | 7b. At what age did you **LAST** play hockey?  Age |  |
| **8. Did you play hockey professionally?**  (**Note:** this ONLY refers to playing in the NHL, AHL, or ECHL)  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 9** | 8a. At what age did you **FIRST** start playing professional hockey?  Age | 8b. At what age did you **LAST** play professional hockey?  Age | 8c. In what league did you play while playing professional hockey?  **(Select all that apply)**  1 NHL  2 AHL  3 ECHL  4 Other: \_\_\_\_\_\_\_\_\_  \*Specify other |
| 8d. What primary position did you play while playing professional hockey?  1 Lt Wing  2 Rt Wing  3 Wing  4 Forward  5 Center  6 Lt Defensemen  7 Rt Defensemen  8 Defensemen  9 Goalie  10 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | 8e. Were you ever an enforcer while playing professional hockey?  1 Yes  2 No  9 Don’t know |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **9. Did you play hockey semi-professionally or at the junior level?**  (**Note:** this does NOT include college or high school teams)  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 10** | 9a. At what age did you **FIRST** start playing semi-professional or junior level hockey?  Age | 9b. At what age did you **LAST** play semi-professional or junior level hockey?    Age |  |
| 9c. What primary position did you play while playing hockey semi-professionally or at the junior level?  1 Lt Wing  2 Rt Wing  3 Wing  4 Forward  5 Center  6 Lt Defensemen  7 Rt Defensemen  8 Defensemen  9 Goalie  10 Other: \_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | 9d. Were you ever an enforcer while playing hockey semi-professionally or at the junior level?  1 Yes  2 No  9 Don’t know |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **10. Did you play hockey in college?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 11** | 10a. At what age did you **FIRST** start playing college hockey?  Age  \*Please do not include years possibly covered by time playing semi-professional or junior level hockey | 10b. At what age did you **LAST** play college hockey?  Age  \*Please do not include years possibly covered by time playing semi-professional or junior level hockey | 10c. In what league did you play while playing college hockey?  **(Select all that apply)**  1 Division I  2 Division II  3 Division III  4 NAIA  5 Other: \_\_\_\_\_\_\_\_\_  9 Don’t know  \*Specify other |
| 10d. What primary position did you play while playing college hockey?  1 Lt Wing  2 Rt Wing  3 Wing  4 Forward  5 Center  6 Lt. Defensemen  7 Rt. Defensemen  8 Defensemen  9 Goalie  10 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | 10e. Were you ever an enforcer while playing college hockey?  1 Yes  2 No  9 Don’t know |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **11. Did you play hockey in high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 12** | 11a. At what age did you **FIRST** start playing high school hockey?  Age  Please include post-graduate year if applicable, but not time played at any previously mentioned level. | 11b. At what age did you **LAST** play high school hockey?  Age  Please include post-graduate year if applicable, but not time played at any previously mentioned level. | 11c. What primary position did you play while playing high school hockey?  1 Lt Wing  2 Rt Wing  3 Wing  4 Forward  5 Center  6 Lt Defensemen  7 Rt Defensemen  8 Defensemen  9 Goalie  10 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other |
| **12. Did you play hockey prior to high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 13** | 12a. At what age did you **FIRST** start playing hockey prior to high school?  Age  Please include post-graduate year if applicable, but not time played at any previously mentioned level. | 12b. At what age did you **LAST** start playing hockey prior to high school?  Age  Please include post-graduate year if applicable, but not time played at any previously mentioned level. | 12c. What primary position did you play while playing hockey prior to high school?  1 Lt Wing  2 Rt Wing  3 Wing  4 Forward  5 Center  6 Lt Defensemen  7 Rt Defensemen  8 Defensemen  9 Goalie  10 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other |

|  |  |  |  |
| --- | --- | --- | --- |
| ORGANIZED BOXING: Q13-Q15 | | | |
| **13. Were you ever a boxer?**  1 Yes 🡪  2 No  9 Don’t know  Note: That boxer refers ONLY to professional or amateur boxing in which you competed in refereed bouts.  If No or Don’t know**, skip to Question 16** | 13a. At what age did you FIRST start boxing?  Age | 13b. At what age did you LAST box?  Age |  |
| **14. Did you ever box professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 15** | 14a. How many total bouts or matches did you compete in while boxing professionally? | 14b. In what weight class did you compete while boxing professionally?  1 Heavyweight  2 Cruiserweight/junior heavyweight  3 Light heavyweight  4 Super middleweight  5 Middleweight  6 Super welterweight, junior/light middleweight  7 Welterweight  8 Super lightweight or junior/light welterweight  9 Lightweight  10 Super featherweight/junior lightweight  11 Featherweight  12 Super bantamweight/junior featherweight  13 Bantamweight  14 Super flyweight/junior bantamweight  15 Flyweight  16 Light flyweight/junior flyweight  17 Minimumweight/mini flyweight/strawweight  18 Light minimumweight/Atomweight  19 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | |

|  |  |  |
| --- | --- | --- |
| **15. Did you ever box as an amateur?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 16** | 15a. How many total bouts or matches did you compete in while boxing as an amateur? | 15b. In what weight class did you compete while boxing as an amateur?  1 Heavyweight  2 Cruiserweight/junior heavyweight  3 Light heavyweight  4 Super middleweight  5 Middleweight  6 Super welterweight, junior/light middleweight  7 Welterweight  8 Super lightweight or junior/light welterweight  9 Lightweight  10 Super featherweight/junior lightweight  11 Featherweight  12 Super bantamweight/junior featherweight  13 Bantamweight  14 Super flyweight/junior bantamweight  15 Flyweight  16 Light flyweight/junior flyweight  17 Minimum weight/mini flyweight/straw weight  18 Light minimumweight/Atomweight  19 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other |

|  |  |  |  |
| --- | --- | --- | --- |
| ORGANIZED SOCCER: Q16-Q | | | |
| **16. Did you ever play organized soccer?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 22** | 16a. At what age did you **FIRST** start playing soccer?  Age | 16b. At what age did you **LAST** play soccer?  Age |  |
| **17. Did you play soccer professionally or semi-professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 18** | 17a. At what age did you **FIRST** start playing soccer professionally or semi-professionally?  Age | 17b. At what age did you **LAST** play soccer professionally or semi-professionally?  Age |  |
| 17c. In what league(s) did you play while playing soccer professionally or semi-professionally?  1 North American🡪  2 South American🡪  3 European 🡪  4 Asian/Australian 🡪  5 African 🡪  6 Other: \_\_\_\_\_\_\_  9 Don’t know  \*Specify other | 17ci. Please **specify** the league(s) you played professional soccer.  NA: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  SA: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Euro: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  A&A: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Afr: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 17d. What was the **primary** position you held while playing soccer professionally or semi-professionally?  1 Defender  2 Center-back  3 Sweeper  4 Full-back/Lt-back/Rt-back  5 Wingback  6 Midfielder  7 Winger/Lt midfield/Rt midfield  8 Defensive midfielder  9 Attacking midfielder  10 Forward  11 Striker  12 Goalie  13 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | |

|  |  |  |  |
| --- | --- | --- | --- |
| **18. Did you play college soccer?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 19** | 18a. At what age did you **FIRST** start playing college soccer?  Age | 18b. At what age did you **LAST** play college soccer?  Age |  |
| 18c. In what league did you play while playing college soccer?  1 Division I  2 Division II  3 Division III  4 NAIA  5 Other: \_\_\_\_\_\_\_  9 Don’t know  \*Specify other | 18d. What was the **primary** position you held while playing college soccer?  1 Defender  2 Center-back  3 Sweeper  4 Full-back/Lt-back/Rt-back  5 Wingback  6 Midfielder  7 Winger/Lt midfield/Rt midfield  8 Defensive midfielder  9 Attacking midfielder  10 Forward  11 Striker  12 Goalie  13 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **19. Did you play soccer in high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 20** | 19a. At what age did you **FIRST** start playing soccer in high school?  Age | 19b. At what age did you **LAST** play soccer in high school?  Age |  |
| 19c. What was the **primary** position you held while playing soccer in high school?  1 Defender  2 Center-back  3 Sweeper  4 Full-back/Lt-back/Rt-back  5 Wingback  6 Midfielder  7 Winger/Lt midfield/Rt midfield  8 Defensive midfielder  9 Attacking midfielder  10 Forward  11 Striker  12 Goalie  13 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **20. Did you play soccer prior to high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 21** | 20a. At what age did you **FIRST** start playing soccer prior to high school?  Age | 20b. At what age did you **LAST** play soccer prior to high school?  Age |  |
| 20c. What was the **primary** position you held while playing soccer prior to high school?  1 Defender  2 Center-back  3 Sweeper  4 Full-back/Lt-back/Rt-back  5 Wingback  6 Midfielder  7 Winger/Lt midfield/Rt midfield  8 Defensive midfielder  9 Attacking midfielder  10 Forward  11 Striker  12 Goalie  13 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | |  |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **21. Did you play soccer at another level?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 22** | 21a. At what age did you **FIRST** start playing soccer at another level?  Age | 21b. At what age did you **LAST** play soccer at another level?  Age |  |
| 21c. What was the **primary** position you held while playing soccer at another level?  1 Defender  2 Center-back  3 Sweeper  4 Full-back/Lt-back/Rt-back  5 Wingback  6 Midfielder  7 Winger/Lt midfield/Rt midfield  8 Defensive midfielder  9 Attacking midfielder  10 Forward  11 Striker  12 Goalie  13 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  99 Don’t know  \*Specify other | |  |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| OTHER ORGANIZED SPORT (A): Q22-Q28 | | | | |
| **22. Did you play any other organized sports?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **END SURVEY.** | 22a. What was your **next, major, organized sport** played? | | | |
| 1 Amateur Wrestling  2 Auto Racing  3 Bandy  4 Baseball  5 Basketball  6 Bodybuilding  7 Bowling  8 Bull Riding  9 Distance Running  10 Crew  11 Cross County  12 Cycling  13 Decathlon  14 Diving  15 Equestrian  16 Field Hockey  17 Flag Football  18 Floor Hockey  ­­19 Golf  20 Gymnastics  21 Horse Jumping  22 Ice Skating  23 Inline Skating  24 Karate  ­­25 Kickball  \*Specify other | | 26 Lacrosse  27 Martial Arts  28 Mixed Martial Arts (MMA)  29 Motorcycle Racing  30 Mountaineering  31 Parachuting  32 Pentathlon  33 Power Lifting  34 Entertainment Wrestling  35 Racquetball  36 Roller Hockey  37 Rugby  38 Skiing  39 Snowboarding  40 Softball  41 Squash  42 Strongman  43 Swimming  ­­44 Tennis  45 Track and Field  46 Triathlon  47 Ultimate Frisbee  48 Water Polo  49 Water Skiing  ­­50 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |
| 22b. At what age did you **FIRST** start playing this organized sport?  Age | 22c. At what age did you **LAST** play this organized sport?  Age |  | |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **23. Did you play this organized sport professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 24** | 23a. How many years did you play this organized sport professionally?  Years | 23b. What was the **primary** position you played while playing this organized sport professionally?  \*If the sport does not have positions please respond N/A |  |
| **24. Did you play this organized sport semi-professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 25** | 24a. How many years did you play this organized sport semi-professionally?  Years | 24b. What was the **primary** position you played while playing this organized sport semi-professionally?  \*If the sport does not have positions please respond N/A |  |
| **25. Did you play this organized sport in college?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 26** | 25a. How many years did you play this organized sport in college?  Years | 25b. What was the **primary** position you played while playing this organized sport in college?  \*If the sport does not have positions please respond N/A |  |
| **26. Did you play this organized sport in high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 27** | 26a. How many years did you play this organized sport in high school?  Years | 26b. What was the **primary** position you played while playing this organized sport in high school?  \*If the sport does not have positions please respond N/A |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **27. Did you play this organized sport before high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 28** | 27a. How many years did you play this organized sport before high school?  Years | 27b. What was the **primary** position you played while playing this organized sport before high school?  \*If the sport does not have positions please respond N/A |  |
| **28. Did you play this organized sport at another level?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 29** | 28a. How many years did you play this organized sport at another level?  Please specify the level:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Years | 28b. What was the **primary** position you played while playing this organized sport before high school?  \*If the sport does not have positions please respond N/A |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| OTHER ORGANIZED SPORT (B): Q29-Q35 | | | | |
| **29. Did you play any other organized sports?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **END SURVEY.** | 29a. What was your **next, major, organized sport** played? | | | |
| 1 Amateur Wrestling  2 Auto Racing  3 Bandy  4 Baseball  5 Basketball  6 Bodybuilding  7 Bowling  8 Bull Riding  9 Distance Running  10 Crew  11 Cross County  12 Cycling  13 Decathlon  14 Diving  15 Equestrian  16 Field Hockey  17 Flag Football  18 Floor Hockey  ­­19 Golf  20 Gymnastics  21 Horse Jumping  22 Ice Skating  23 Inline Skating  24 Karate  ­­25 Kickball  \*Specify other | | 26 Lacrosse  27 Martial Arts  28 Mixed Martial Arts (MMA)  29 Motorcycle Racing  30 Mountaineering  31 Parachuting  32 Pentathlon  33 Power Lifting  34 Entertainment Wrestling  35 Racquetball  36 Roller Hockey  37 Rugby  38 Skiing  39 Snowboarding  40 Softball  41 Squash  42 Strongman  43 Swimming  ­­44 Tennis  45 Track and Field  46 Triathlon  47 Ultimate Frisbee  48 Water Polo  49 Water Skiing  ­­50 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |
| 29b. At what age did you **FIRST** start playing this organized sport?  Age | 29c. At what age did you **LAST** play this organized sport?  Age |  | |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **30. Did you play this organized sport professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 31** | 30a. How many years did you play this organized sport professionally?  Years | 30b. What was the **primary** position you played while playing this organized sport professionally?  \*If the sport does not have positions please respond N/A |  |
| **31. Did you play this organized sport semi-professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 32** | 31a. How many years did you play this organized sport semi-professionally?  Years | 31b. What was the **primary** position you played while playing this organized sport semi-professionally?  \*If the sport does not have positions please respond N/A |  |
| **32. Did you play this organized sport in college?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 33** | 32a. How many years did you play this organized sport in college?  Years | 32b. What was the **primary** position you played while playing this organized sport in college?  \*If the sport does not have positions please respond N/A |  |
| **33. Did you play this organized sport in high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 34** | 33a. How many years did you play this organized sport in high school?  Years | 33b. What was the **primary** position you played while playing this organized sport in high school?  \*If the sport does not have positions please respond N/A |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **34. Did you play this organized sport before high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 35** | 34a. How many years did you play this organized sport before high school?  Years | 34b. What was the **primary** position you played while playing this organized sport before high school?  \*If the sport does not have positions please respond N/A |  |
| **35. Did you play this organized sport at another level?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 36** | 35a. How many years did you play this organized sport at another level?  Please specify the level:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Years | 35b. What was the **primary** position you played while playing this organized sport before high school?  \*If the sport does not have positions please respond N/A |  |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| OTHER ORGANIZED SPORT (C): Q36-Q42 | | | | |
| **36. Did you play any other organized sports?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **END SURVEY** | 36a. What was your **next, major, organized sport** played? | | | |
| 1 Amateur Wrestling  2 Auto Racing  3 Bandy  4 Baseball  5 Basketball  6 Bodybuilding  7 Bowling  8 Bull Riding  9 Distance Running  10 Crew  11 Cross County  12 Cycling  13 Decathlon  14 Diving  15 Equestrian  16 Field Hockey  17 Flag Football  18 Floor Hockey  ­­19 Golf  20 Gymnastics  21 Horse Jumping  22 Ice Skating  23 Inline Skating  24 Karate  ­­25 Kickball  \*Specify other | | 26 Lacrosse  27 Martial Arts  28 Mixed Martial Arts (MMA)  29 Motorcycle Racing  30 Mountaineering  31 Parachuting  32 Pentathlon  33 Power Lifting  34 Entertainment Wrestling  35 Racquetball  36 Roller Hockey  37 Rugby  38 Skiing  39 Snowboarding  40 Softball  41 Squash  42 Strongman  43 Swimming  ­­44 Tennis  45 Track and Field  46 Triathlon  47 Ultimate Frisbee  48 Water Polo  49 Water Skiing  ­­50 Other: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |
| 36b. At what age did you **FIRST** start playing this organized sport?  Age | 36c. At what age did you **LAST** play this organized sport?  Age |  | |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **37. Did you play this organized sport professionally?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 38** | 37a. How many years did you play this organized sport professionally?  Years | 37b. What was the **primary** position you played while playing this organized sport professionally?  \*If the sport does not have positions please respond N/A |  |
| **38. Did you play this organized sport semi-professionally?**  1 Yes **🡪**  2 No **🡪**  9 Don’t know  If No or Don’t know, **skip to Question 39** | 38a. How many years did you play this organized sport semi-professionally?  Years | 38b. What was the **primary** position you played while playing this organized sport semi-professionally?  \*If the sport does not have positions please respond N/A |  |
| **39. Did you play this organized sport in college?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 40** | 39a. How many years did you play this organized sport in college?  Years | 39b. What was the **primary** position you played while playing this organized sport in college?  \*If the sport does not have positions please respond N/A |  |
| **40. Did you play this organized sport in high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 41** | 40a. How many years did you play this organized sport in high school?  Years | 40b. What was the **primary** position you played while playing this organized sport in high school?  \*If the sport does not have positions please respond N/A |  |

|  |  |  |  |
| --- | --- | --- | --- |
| **41. Did you play this organized sport before high school?**  1 Yes **🡪**  2 No  9 Don’t know  If No or Don’t know, **skip to Question 42** | 41a. How many years did you play this organized sport before high school?  Years | 41b. What was the **primary** position you played while playing this organized sport before high school?  \*If the sport does not have positions please respond N/A |  |
| **42. Did you play this organized sport at another level?**  1 Yes **🡪**  2 No  9 Don’t know | 42a. How many years did you play this organized sport at another level?  Please specify the level:  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Years | 42b. What was the **primary** position you played while playing this organized sport before high school?  \*If the sport does not have positions please respond N/A |  |

## ALS-ASSOCIATED AND CLINICAL FACTORS

SURVEY 6: FAMILY HISTORY

The following questions relate to biological family members including parents, sisters and brothers (including half siblings) and children. Please **do not** include adopted relatives.

1. How many biological sisters (including half-sisters) do you have, living or deceased?

🖵🖵 number

2. How many biological brothers (including half-brothers) do you have, living or deceased?

🖵🖵 number

3. How many biological children do you have, living or deceased?

🖵🖵 number

Please complete a few questions about **each** of your immediate relatives with respect to particular medical conditions they may have had. Among your biological relatives, including your parents, sisters, brothers and children, has anyone ever been diagnosed by a physician with any of the following conditions?

Relationship: Mother

1. Is your mother still living?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2. What is your mother’s current age or age at her death? 🖵🖵 years old

3. Has your mother ever been diagnosed by a physician with any of the following medical conditions?

Amyotrophic lateral sclerosis: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Alzheimer’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Parkinson’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

4. At what age was she diagnosed with the condition?

🖵🖵 age (ALS) 🖵 Don’t know

🖵🖵 age (Alzheimer’s) 🖵 Don’t know

🖵🖵 age (Parkinson’s) 🖵 Don’t know

Relationship: Father

1. Is your father still living?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2. What is your father’s current age or age at his death? 🖵🖵 years old

3. Has your father ever been diagnosed by a physician with any of the following medical conditions?

Amyotrophic lateral sclerosis: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Alzheimer’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Parkinson’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

4. At what age was he diagnosed with the condition?

🖵🖵 age (ALS) 🖵 Don’t know

🖵🖵 age (Alzheimer’s) 🖵 Don’t know

🖵🖵 age (Parkinson’s) 🖵 Don’t know

Relationship: Sibling (sister)

1. Is your sister still living?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2. What is your sister’s current age or age at her death? 🖵🖵 years old

3. Has your sister ever been diagnosed by a physician with any of the following medical conditions?

Amyotrophic lateral sclerosis: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Alzheimer’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Parkinson’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

4. At what age was she diagnosed with the condition?

🖵🖵 age (ALS) 🖵 Don’t know

🖵🖵 age (Alzheimer’s) 🖵 Don’t know

🖵🖵 age (Parkinson’s) 🖵 Don’t know

Relationship: Sibling (brother)

1. Is your brother still living?

1🖵 Yes 2🖵 No 9🖵 Don’t know

2. What is your brother’s current age or age at his death? 🖵🖵 years old

3. Has your brother ever been diagnosed by a physician with any of the following medical conditions?

Amyotrophic lateral sclerosis: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Alzheimer’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Parkinson’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

4. At what age was he diagnosed with the condition?

🖵🖵 age (ALS) 🖵 Don’t know

🖵🖵 age (Alzheimer’s) 🖵 Don’t know

🖵🖵 age (Parkinson’s) 🖵 Don’t know

Relationship: Children

1. Relationship: 1🖵 Daughter 2🖵 Son

2. Is your child still living? 1🖵 Yes 2🖵 No 9🖵 Don’t know

3. What is your child’s current age or the age at his/her death? 🖵🖵 years old

4. Has your child ever been diagnosed by a physician with any of the following medical conditions?

Amyotrophic lateral sclerosis: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Alzheimer’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

Parkinson’s disease: 1🖵 Yes 2🖵 No 9🖵 Don’t know

1. At what age was he/she diagnosed with the condition?

🖵🖵 age (ALS) 🖵 Don’t know

🖵🖵 age (Alzheimer’s) 🖵 Don’t know

🖵🖵 age (Parkinson’s) 🖵 Don’t know

Note Survey 7 is at the end because it is the only survey taken more than once.

SURVEY 17: FIRST NOTICED SYMPTOMS

**1. When did you first notice weakness that was later diagnosed as ALS?**

🖵🖵 / 🖵🖵 🖵 Don’t know

MONTH YEAR

2. In what part of the body did you first notice weakness that was diagnosed as ALS?

Speech and/or swallowing muscles

Arm or hand

Neck, back or abdominal area

Leg or foot

Breathing muscles

All over my body

**3. Before you noticed weakness that turned out to be ALS, did you experience any of the following?**

|  |  |
| --- | --- |
| Cramps or muscle spasms?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first experience **cramps or muscle spasms**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Scattered muscle twitching?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first experience **scattered muscle twitching**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Difficulty swallowing?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first experience **difficulty swallowing**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Problems with speech?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first experience **problems with speech**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Difficulty controlling bowels or bladder?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first experience **difficulty controlling bowels or bladder**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |

**4. The following questions are about ALS specific medications you may have taken:**

**4a. Have you taken the drug riluzole (Rilutek®)?**

I have never taken riluzole

I used to take riluzole but discontinued it

I am currently taking riluzole

Don’t know

**4b. Have you taken the drug edaravone (Radicava®)?**

I have never taken edaravone

I used to take edaravone but discontinued it

I am currently taking edaravone

Don’t know

**5. The following questions are about assistive devices or programs you may have used.**

|  |  |
| --- | --- |
| Have you ever used a power wheelchair or electric scooter?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first use **a power wheelchair or electric scooter**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Have you ever used noninvasive breathing equipment, such as Bi-Pap (Bi-level Positive Airway Pressure)?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first use **noninvasive breathing equipment such as Bi-Pap**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Have you ever had a tracheostomy?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you have the **tracheostomy**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Have you ever used an augmentative and alternative communication device?  1🖵 Yes 🡺 \_text box\_  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first use an **augmentative and alternative communication device**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |
| Have you ever been enrolled in a hospice program?  1🖵 Yes 🡺  2🖵 No  9🖵 Don’t know | **IF YES**  In what month and year did you first enroll in a **hospice program**?  🖵🖵 / 🖵🖵 🖵 Don’t know  MONTH YEAR |

**6. Since you developed ALS, have you had any of the following (mark all that apply):**

Pneumonia that required treatment with prescription medication yes/no/don’t know

Falls that caused injury significant enough that you were seen by a physician yes/no/don’t know

A blood clot in an arm, leg or in the lung that required treatment with blood thinner medication yes/no/don’t know

7. Have you participated in any ALS research studies?

No/Yes

Don’t know

Would you potentially be interested in participating in ALS research studies?

No/Yes

Don’t know

**8. A multidisciplinary ALS clinic is a clinic in which specialized medical care is provided at a medical facility by a team of healthcare professionals. This team may include a neurologist, nurse, physical therapist, occupational therapist, respiratory therapist, speech-language pathologist, nutritionist or dietitian and social worker.**

**Have you attended an ALS multidisciplinary clinic?**

I have never attended a multidisciplinary ALS clinic

I currently attend a multidisciplinary ALS clinic

I previously attended a multidisciplinary ALS clinic but do not plan to attend any further visits

Don’t know

**9. Which hand do/did you write with?**

Right

Left

Can use either equally well

**10. Do you have advance directives established, such as a living will?**

No/Yes

Don’t know

**11. Have you had genetic test for inherited traits that can cause ALS?**

No/Yes

Don’t know

Self-Administered Rating Scale (to be completed 3 times in the first year and ever 6 months thereafter)

SURVEY 7: FUNCTIONAL CHANGES

The following rating scale is used to assess changes in physical functioning in persons with ALS and other motor neuron diseases.

The questions refer to how you are currently functioning at home. Please read each item carefully and base your answers on your functioning today compared to the time before you had any symptoms of ALS or another motor neuron disease. Please choose the answer that best fits your functional status today.

Compared with the time before you had symptoms of ALS or another motor neuron disease:

1. Have you noticed any changes in your speech?

|  |  |
| --- | --- |
|  | No change |
|  | I have a noticeable speech difference. |
|  | My speech has changed. I am asked often to repeat words or phrases. |
|  | My speech has changed. I sometimes need the use of alternative communication methods (i.e. computer, writing pad, letter board or eye chart). |
|  | I am unable to communicate verbally. |

2. Have you noticed any changes (increases) in the amount of saliva in your mouth (regardless of any medication use)?

|  |  |
| --- | --- |
|  | No change |
|  | I have slight but definite excess of saliva with or without night time drooling. |
|  | I have moderate amounts of excessive saliva with or without minimal day time drooling. |
|  | I have marked amounts of excessive saliva with some daytime drooling. |
|  | I have marked excessive saliva with marked drooling requiring a constant tissue or handkerchief. |

Compared with the time before you had symptoms of ALS or another motor neuron disease:

3. Have there been any changes in your ability to swallow?

|  |  |
| --- | --- |
|  | No changes for all foods and liquids |
|  | I have some changes in swallowing or occasional choking episodes (including coughing during swallowing). |
|  | I am unable to eat all consistencies of food and have modified the consistency of foods eaten. |
|  | I use a feeding tube (PEG) to supplement what is eaten by mouth. |
|  | I do not eat anything by mouth and receive all nutrition through a feeding tube (PEG). |

4. Has your handwriting changed? Please choose the best answer that describes your handwriting with your dominant (usual) hand without a cuff or brace.

|  |  |
| --- | --- |
|  | No changes |
|  | My handwriting is slower and/or sloppier but all the words are legible. |
|  | Not all my words are legible. |
|  | I am able to hold a pen but unable to write. |
|  | I am unable to hold a pen. |

The following question refers to your ability to cut foods and handle utensils (feed yourself).

Compared with the time before you had symptoms of ALS or another motor neuron disease:

5. How do you get most of your nutrition?

|  |  |
| --- | --- |
|  | Eat most of my meals by mouth |
|  | Get most of my nutrition through a feeding tube (PEG) |

6. Cutting food and handling utensils:

|  |  |
| --- | --- |
|  | No change |
|  | My cutting food or handling utensils is somewhat slow and clumsy (or different than before) but I do not need assistance or adaptive equipment. |
|  | I sometimes need help with cutting more difficult foods. |
|  | My food must be cut by someone else but I can feed myself slowly without assistance. |
|  | I need to be fed. |

7. Using a feeding tube (PEG)

|  |  |
| --- | --- |
|  | I use a PEG without assistance or difficulty. |
|  | I use a PEG without assistance however I may be slow and /or clumsy. |
|  | I require assistance with closures and fasteners. |
|  | I provide minimal assistance to a caregiver. |
|  | I am unable to perform any of the manipulations. |

Compared with the time before you had symptoms of ALS or another motor neuron disease:

8. Has your ability to dress and perform self-care activities (i.e. bathing, teeth brushing, shaving, combing your hair, other hygienic activities) changed?

|  |  |
| --- | --- |
|  | No change |
|  | I perform self-care activities without assistance but with increased effort or decreased efficiency. |
|  | I require intermittent assistance or use different methods (i.e. sit down to get dressed, fasten buttons with a fastener or your non-dominant hand). |
|  | I require daily assistance. |
|  | I do not perform self-care activities and am completely dependent on caregiver. |

9. Has your ability to turn in bed and adjust the bed clothes (i.e. cover yourself with the sheet or blanket) changed?

|  |  |
| --- | --- |
|  | No change |
|  | I can turn in bed and adjust the bed clothes without assistance but it is slower or more clumsy. |
|  | I can turn in bed or adjust the bed clothes without assistance but with great difficulty. |
|  | I can initiate turning in bed or adjusting the bed clothes but require assistance to complete the task. |
|  | I am helpless in bed. |

Compared with the time before you had symptoms of ALS or another motor neuron disease:

10. Has your ability to walk changed?

|  |  |
| --- | --- |
|  | No change |
|  | My walking has changed but I do not require any assistance or devices (i.e. foot brace, cane, or walker). |
|  | I require assistance to walk (i.e. cane, walker, foot brace or hand held assistance). |
|  | I can move my legs or stand up but am unable to walk from room to room. |
|  | I cannot walk or move my legs. |

11. Has your ability to climb stairs changed?

|  |  |
| --- | --- |
|  | No change |
|  | I am slower. |
|  | I am unsteady and/or more fatigued. |
|  | I require assistance (i.e. using the handrail, cane or person). |
|  | I cannot climb stairs. |

Compared with the time before you had symptoms of ALS or another motor neuron disease:

12. Do you experience shortness of breath or have difficulty breathing?

|  |  |
| --- | --- |
|  | No change |
|  | I have shortness of breath only with walking. |
|  | I have shortness of breath with minimal exertion (i.e. talking, eating, bathing or dressing). |
|  | I have shortness of breath at rest while either sitting or lying down. |
|  | I have significant shortness of breath (all of the time) and considering using mechanical ventilation. |

13. Do you experience shortness of breath or have difficulty breathing while lying down on your back?

|  |  |
| --- | --- |
|  | No change |
|  | I occasionally have shortness of breath while lying on back but don’t routinely use more that two (2) pillows to sleep. |
|  | I have shortness of breath while lying on back and require more than two pillows (or an equivalent) to sleep. |
|  | I can only sleep sitting up due to shortness of breath. |
|  | I require the use of respiratory (breathing) support (BiPAP® or invasive ventilation via tracheostomy) to sleep and do not sleep without it. |

14. Do you require respiratory (breathing) support?

|  |  |
| --- | --- |
|  | I need no respiratory support. |
|  | I need intermittent use of BiPAP®. |
|  | I need continuous use of BiPAP® at night. |
|  | I need continuous use of BiPAP® at night and during the day (nearly 24 hours per day). |
|  | I need mechanical ventilation by intubation or tracheostomy. |

15. Please indicate who completed this survey:

|  |  |
| --- | --- |
|  | I completed the survey (patient). |
|  | I completed the survey with assistance. |
|  | I completed the survey with assistance from caregiver or family member. |
|  | The caregiver completed the survey alone. |

16. What is your current weight? \_\_ \_\_ \_\_ lbs

17. Have you been hospitalized in the past 6 months? Yes  No

18. If yes, how many times were you in the hospital? \_\_ \_\_ number of times

19. How many days were you hospitalized? \_\_ \_\_ total number of days

20. Have you gone to the Emergency Room in the past 6 months? Yes  No

21. If yes, how many times have you visited the Emergency Room? \_\_ \_\_ number of times

SURVEY16: OPEN ENDED QUESTIONS

1. Please enter your ideas or thoughts regarding the factors that may have caused your ALS.

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2. Please enter any ideas about factors that may cause ALS in general.

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